

## Trends in place of death in New Jersey: An analysis of death certificates

Katherine Hempstead, PhD

**Abstract:** There is considerable interest in the place of death as a potential indicator of the quality of medical care, particularly in the case of terminal conditions. Evidence suggests that many terminally ill patients prefer to die at home. Yet while there have been studies of patients' preferences, there has been relatively little systematic examination of death certificates, a major source of information on place of death. This analysis of New Jersey death certificates describes trends over time in place of death, and differences by age, sex, race and cause of death. Between 1989 and 1998, the proportion of deaths which occurred to decedents who were hospital inpatients decreased considerably, while the proportion which occurred in the decedent's residence and in nursing homes has increased. There are significant variations in this pattern by age, race, and county of residence, as well as by cause of death.

### I. Introduction

The rising share of all deaths occurring from chronic and long-term illnesses has increased interest in the place of death as a potential measure of the quality of medical care. While those who die as a result of an injury or acute illness have little or no choice over where they die, terminally ill patients may conceivably spend their last days in a hospital, their residence, or some other type of long term-care facility such as a nursing home or hospice. Even among chronic conditions, the relationship between place of death and quality of medical care is not straightforward. In the case of deaths resulting from cancer or HIV/AIDS, an increase in the proportion of deaths occurring at home or outside of a hospital would be interpreted by many as a sign of improvement in the quality of end-of-life care. On the other hand, for chronic conditions that are not necessarily terminal, the implications of such a pattern could be quite different, and may instead be suggestive of inadequate preventive care or premature discharge, especially if accompanied by an overall increase in cause-specific mortality rates. A decline in the share of dead on arrival (D.O.A.) deaths suggests an improvement in the quality of care provided by paramedics, or perhaps an underlying increase in preventive care. The overall distribution of death by place in a population is primarily a function of the population's cause of death structure, which is most influenced by the age composition. In an aging industrialized population such as that of the United States, an increasing proportion of deaths are from terminal illnesses such as cancer. Additionally, a growing share of the population may reside in nursing

homes. Yet the recent epidemic of HIV/AIDS has greatly increased the importance of terminal illness among younger age groups.

However, despite the importance of place of death as a potential indicator of quality of medical care, research on place of death and its determinants has been minimal. While there have been studies of patients' desires and caregivers' attitudes, there has been relatively little analysis of death certificates, a major source of information of place of death. This analysis of New Jersey death certificates describes trends over time in place of death, and important variations by age, sex, race and cause of death. Additionally, a random sample of certificates where the place of death is indicated as "other" is examined and results are described. The proportion of deaths occurring in the decedent's residence and in nursing homes has increased while that occurring to hospital inpatients has decreased. There are significant variations by age and by race, as well as by cause of death.

## II. Background

Research among the critically ill and their relatives has found that preference for home as a location for terminal care and death exceeds current practice.<sup>1,2,3</sup> There are several identified determinants of preference for dying in one's home, mostly related to knowledge of options and existence of family members who can provide care. One study of cancer patients in Israel found that the age of the patient and the existence of extended family influenced where respondents chose to die.<sup>4</sup> Another suggested that those with more awareness of their impending death were more likely to express a preference about the location of their death.<sup>5</sup>

However patients' desire to die at home is not universal. A recent study of seriously ill patients found that dying at home was considered less important than many other factors such as pain relief, or achieving a "sense of completion" before death. In fact the desire to die at home was rated the least important of nine major attributes of death presented to patients<sup>6</sup>. The authors note that, "The notion of dying at home may be romantic among health care professionals who want to provide a good death. However, as symptoms accelerate in the last 24 to 48 hours, some patients and families may feel overwhelmed by concerns about symptom control or a dead body in the home and, therefore, prefer a skilled care environment." Another study of patients with terminal cancer found that a majority of those advised by their physicians to enter hospice care for palliative treatment rejected this advice in favor of more aggressive hospital-based treatment.<sup>7</sup>

Preference for dying at home and use of end-of-life planning in general appears to be lower among blacks than for the population as a whole. For example, a recent U.S. study found blacks to be less likely than whites to be aware of and to be desirous of adopting such end-of-life directives such as Do Not Resuscitate orders.<sup>8</sup> Results from a recent telephone survey of New Jersey adults found that 23% of blacks versus 17% of whites responded that if faced with a terminal illness they would be inclined to "extend life as long as possible even if meant more patient discomfort." Similarly, only 52% of blacks as opposed to 69% of whites reported that they'd spoken to someone close to them about their wishes for treatment during a life threatening illness.<sup>9</sup> While the cause of these racial differences is not well understood, the newly formed Initiative to Improve Palliative and End-of-Life Care in the Black Community has issued a

report suggesting that cultural as well as economic factors are important. This group advocates further study of the determinants of these racial differences, the education of patients and professionals, and the creation of public policy designed to enhance awareness and acceptability of palliative care and end of life directives among blacks.<sup>10</sup>

While patients' stated preferences have an influence on place of death, for a variety of reasons patients' wishes are not always followed.<sup>11</sup> Place of death is also affected by availability of sufficient financial resources and family support.<sup>12</sup> A study of HIV patients in London showed that unexpected deteriorations in health can mitigate stated preferences to die at home - and that a high proportion of deaths occurring in the hospital are unplanned.<sup>13</sup> A major research effort based in five U.S. teaching hospitals used Medicare data and data on patient preferences to analyze determinants of place of death. Strikingly, they found that the existence of acute care hospital beds was a significant determinant; locations with more hospice and nursing home availability had more out of hospital deaths than did others. In fact, these characteristics of the local health system were found to be the most important determinant of place of death, but the relationship between individual preferences and the characteristics of local health systems is poorly understood and potentially endogenous.<sup>14</sup> This finding is consistent with other research, which has found a relationship between practice style and the local infrastructure of medical facilities and technology. A study of geographical variation in place of death in Italy yielded similar results.<sup>15</sup>

### III. Trends in Place of Death in New Jersey

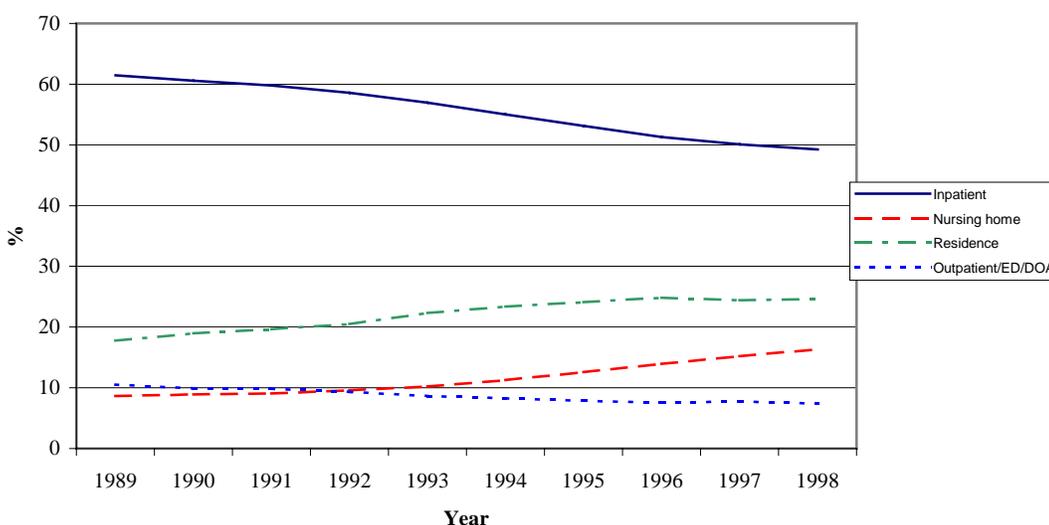
The New Jersey death certificate lists six possibilities for place of death: inpatient, emergency room or outpatient, D.O.A., nursing home, residence, or other. In less than one percent of certificates, information on place of death is missing. The proposed new standard death certificate, to be adopted in 2003, will have a separate category for "hospice" as a place of death. A relatively small share (approximately 10%) of those who were coded as dying in an "other" place in fact died in a hospice or some other type of care facility that did not fit the standards of a hospital or nursing home. However, many of those who die at home receive in-home hospice care. The addition of this proposed item to the death certificate, therefore, would not provide an inclusive measurement of the extent of hospice care.

**Table 1: Distribution by place of death, New Jersey, 1989-1998**

<b>Place of Death</b>	<b>1989</b>	<b>1990</b>	<b>1991</b>	<b>1992</b>	<b>1993</b>	<b>1994</b>	<b>1995</b>	<b>1996</b>	<b>1997</b>	<b>1998</b>
<b>Inpatient</b>	61.44	60.55	59.76	58.57	56.97	55.02	53.12	51.28	50.11	49.27
<b>Outpatient or ED</b>	6.81	6.78	7.03	6.8	6.58	6.26	6.09	6.03	6.24	6.01
<b>Dead on arrival</b>	3.7	3.1	2.8	2.51	2.06	2.02	1.78	1.53	1.49	1.38
<b>Nursing home</b>	8.62	8.89	9.04	9.59	10.22	11.29	12.58	13.95	15.18	16.36
<b>Residence</b>	17.75	18.97	19.64	20.5	22.32	23.35	24.09	24.81	24.44	24.6
<b>Other</b>	1.61	1.66	1.69	1.91	1.75	1.99	2.18	2.29	2.44	2.33

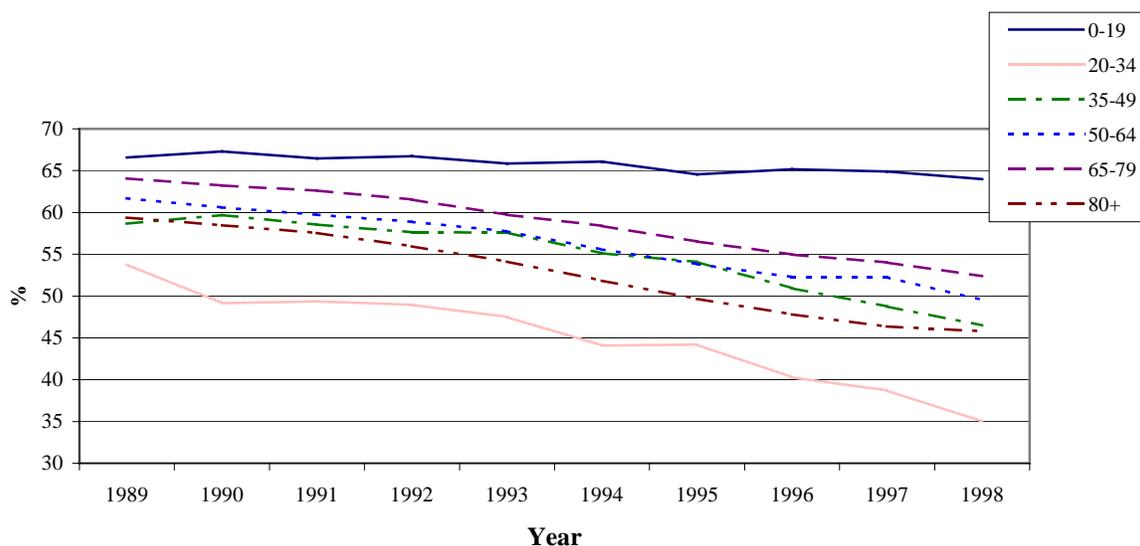
Between 1989 and 1998, the distribution of death by place by death changed considerably, as can be seen in Table and Figure 1. In particular, the proportion of decedents dying while inpatients declined markedly, from 61.4% of all deaths in 1989 to 49.3% in 1998.

**Figure 1: Place of death, New Jersey, 1989-98**



At the same time there was a relatively large increase in the proportion of deaths occurring in the decedent's residence - from 17.8% in 1989 to 24.6% in 1998. Additionally, the importance of nursing homes as a place of death increased. Nursing homes were the location of 8.6 % of all deaths in 1989, and nearly twice that, 16.4% by 1998. The proportion of deaths occurring in some "other" location remained a relatively small share of all deaths (2.3% in 1998), but increased somewhat from 1.6% in 1989. Finally, the proportion of deaths, which occurred in outpatient/emergency department settings or were classified as D.O.A. declined substantially during this period. These last two changes can probably be attributed to improvements in emergency medical services.

Data from 1998 highlights the extent to which place of death varies by age. Young adult decedents (age 20-34 years) are considerably more likely than others to die outside of the hospital. In particular, dying in an "other" location was most common among this group, relative to other age groups, and the decedent's residence is the location of a relatively high proportion of deaths. Decedents aged 35-49 and 50-64 are even more likely to die in their own residence, but are also more likely than those aged 20-34 years to die as inpatients. There are relatively few deaths in "other" locations and in nursing homes for decedents aged 35-64 years. Not surprisingly, deaths in nursing homes are most likely by far for the oldest age group. In fact, the nursing home outranks the residence as a location of death for those aged 80 years and older. The changing role of the outpatient/D.O.A. category reflects age differences in the cause of death. For the first two age categories, deaths in these locations primarily reflect various forms of

**Figure 2: Percent dying as inpatients by age, 1989-98**

injury. For the middle two age groups, heart disease is another important cause of deaths occurring in these locations. These data are shown in Table 2.

**Table 2: Place of death by age, New Jersey, 1998**

Place of Death	Age in years					
	0-19	20-34	35-49	50-64	65-79	80+
<b>Inpatient</b>	<b>65.94</b>	<b>36.21</b>	<b>47.83</b>	<b>50.75</b>	<b>53.02</b>	<b>46.01</b>
<b>Outpatient or ED</b>	<b>13.95</b>	<b>14.32</b>	<b>11.86</b>	<b>9.02</b>	<b>6.09</b>	<b>3.53</b>
<b>Dead on arrival</b>	<b>5.19</b>	<b>7.99</b>	<b>3.73</b>	<b>2.22</b>	<b>1.07</b>	<b>0.57</b>
<b>Nursing home</b>	<b>0.65</b>	<b>1.67</b>	<b>2.94</b>	<b>4.76</b>	<b>10.35</b>	<b>27.7</b>
<b>Residence</b>	<b>8.11</b>	<b>22.31</b>	<b>26.6</b>	<b>30.52</b>	<b>27.79</b>	<b>20.84</b>
<b>Other</b>	<b>6.16</b>	<b>17.23</b>	<b>6.99</b>	<b>2.6</b>	<b>1.6</b>	<b>1.31</b>

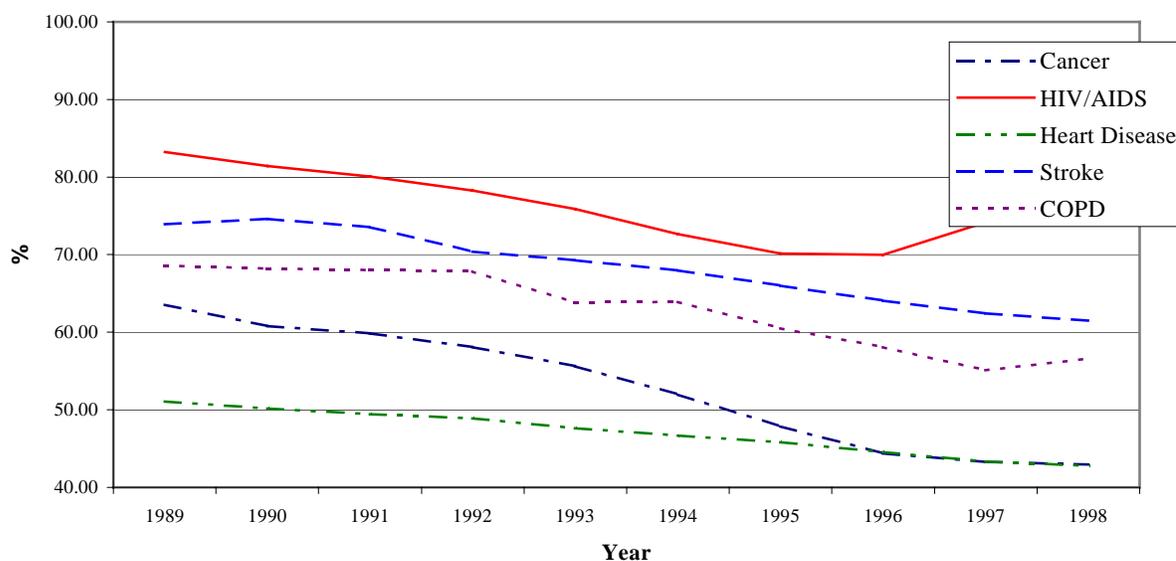
Differences in place of death by race and ethnicity are significant. As can be seen in Table 3, whites are the least likely to die as inpatients and the most likely to die in their residence relative to blacks, Asians, and Hispanics<sup>1</sup>. Asians are second most likely to die at home, and are least likely to die in nursing homes. In part this is due to the age composition of this population, which is relatively young, but it may also reflect cultural values and the relative predominance of multigenerational extended families. Blacks are second most likely to die in nursing homes, while Hispanics are most likely to die as inpatients.

<sup>1</sup> Whites, blacks and Asians exclude Hispanics, who can be of any race. Under reporting or miscoding of Hispanic ethnicity on NJ death certificates affects the accuracy of mortality statistics for different racial and ethnic groups. While virtually all decedents who are coded as Hispanic are in fact Hispanic, the significance of these reporting errors is that a small proportion of decedents in non-Hispanic categories are actually Hispanic. If these errors were to be corrected, differences between Hispanics and other groups would probably become somewhat larger than the uncorrected data suggest, assuming that miscoded Hispanic decedents are a random sample of all Hispanic decedents. Under-reporting of Asian/Pacific Islander race on death certificates also occurs, with similar implications.

**Table 3: Place of death by race and ethnicity, New Jersey, 1998**

Place of Death	Non-Hispanic			Hispanic
	White	Black	Asian	
<b>Inpatient</b>	<b>46.52</b>	<b>59.78</b>	<b>58.87</b>	<b>62.46</b>
<b>Outpatient or ED</b>	<b>5.62</b>	<b>7.57</b>	<b>10.1</b>	<b>7.16</b>
<b>Dead on arrival</b>	<b>1.22</b>	<b>1.86</b>	<b>1.01</b>	<b>2.42</b>
<b>Nursing home</b>	<b>18.3</b>	<b>9.24</b>	<b>5.19</b>	<b>7.99</b>
<b>Residence</b>	<b>26.43</b>	<b>19.35</b>	<b>22.8</b>	<b>12.84</b>
<b>Other</b>	<b>2.02</b>	<b>2.18</b>	<b>2.02</b>	<b>6.22</b>

A major source of the decline in the inpatient share of deaths occurs among those who died from cancer. Figure 3 shows the trend in place of death for cancer deaths and several other major causes between 1989 and 1998. The apparent substitution of residence for the hospital as a place of death is sharper for cancer than for HIV/AIDS, heart disease, stroke or COPD.

**Figure 3: Percent dying as inpatients, selected major causes, New Jersey, 1989-1998**

Interestingly, deaths from HIV/AIDS, a terminal illness of long duration were relatively likely to occur in the hospital; in fact, of all of the major causes shown in Table 4, the proportion of HIV/AIDS deaths occurring in the hospital was higher than that for any other of the causes

listed. Similarly, the decline in the proportion of deaths occurring to inpatients was less sharp for HIV/AIDs than for cancer, heart disease, stroke or COPD.

**Table 4: Place of death for selected major causes, New Jersey, 1998**

Place of Death	Cancer	Heart			COPD
		HIV/AIDS	Disease	Stroke	
<b>Inpatient</b>	<b>42.95</b>	<b>74.07</b>	<b>42.78</b>	<b>61.49</b>	<b>56.60</b>
<b>Outpatient or ED</b>	<b>1.35</b>	<b>2.65</b>	<b>10.28</b>	<b>2.54</b>	<b>4.93</b>
<b>Dead on arrival</b>	<b>0.25</b>	<b>0.26</b>	<b>2.06</b>	<b>0.37</b>	<b>0.59</b>
<b>Nursing home</b>	<b>12.58</b>	<b>6.35</b>	<b>19.28</b>	<b>23.44</b>	<b>15.94</b>
<b>Residence</b>	<b>40.66</b>	<b>14.81</b>	<b>24.06</b>	<b>11.40</b>	<b>20.87</b>
<b>Other</b>	<b>2.13</b>	<b>1.85</b>	<b>1.50</b>	<b>0.73</b>	<b>1.00</b>

Table 5 shows place of death by age exclusively for cancer deaths, thereby controlling for some of the sources of variation in place of death by age which are attributable to age differences in cause of death itself. The significance of the inpatient bed as a place of death from cancer declines steadily with age, while the nursing home and residence increase in significance. Those aged 20-34 years were more likely than were those in other age groups to die as inpatients, a stark contrast to the age pattern for all causes combined revealed in Table 2. For decedents aged 80 years and up, the proportion of deaths occurring in the decedent's residence is higher than the proportion occurring in inpatient units.

**Table 5: Place of death from cancer by age, New Jersey, 1998**

Place of Death	Age in years					
	0-19	20-34	35-49	50-64	65-79	80+
<b>Inpatient</b>	<b>54.84</b>	<b>58.11</b>	<b>53.67</b>	<b>48.29</b>	<b>43.95</b>	<b>34.84</b>
<b>Outpatient or ED</b>	<b>3.23</b>	<b>2.03</b>	<b>2.06</b>	<b>1.27</b>	<b>1.59</b>	<b>0.84</b>
<b>Dead on arrival</b>	<b>0.00</b>	<b>0.00</b>	<b>0.29</b>	<b>0.40</b>	<b>0.19</b>	<b>0.26</b>
<b>Nursing home</b>	<b>1.61</b>	<b>2.70</b>	<b>4.70</b>	<b>6.13</b>	<b>10.32</b>	<b>22.74</b>
<b>Residence</b>	<b>38.71</b>	<b>37.16</b>	<b>37.51</b>	<b>42.41</b>	<b>41.81</b>	<b>38.37</b>
<b>Other</b>	<b>1.61</b>	<b>0.00</b>	<b>1.76</b>	<b>1.44</b>	<b>2.09</b>	<b>2.81</b>

Controlling for cause of death again in Table 6, it can be seen that some of the fundamental differences by race and ethnicity remain, and are not functions of racial and ethnic differences in cause of death. The Hispanic population is the most likely to die as inpatients and least likely to die in their residence, for cancer deaths as is the case for deaths from all causes. Asians are least likely to die in nursing homes and more likely to die at home than are blacks and Hispanics. However, age differences between groups may still affect differences in place of death.

Finally, to further investigate the actual place of death for those coded as "other", samples of approximately 200 certificates were drawn for deaths occurring in 1993, 1995, and 1997. The distribution of "other" deaths by major category has remained relatively constant. The largest

category were those deaths that occurred in some type of residence that was not the decedent's residence, often that of a relative, a hotel, guest home or some other temporary setting. Another major category was various outdoor locations. Often these are at the scene of an accident, drowning, or some other type of adverse event. A relatively small proportion of these deaths, slightly more than 10%, occurs in care facilities that are neither hospitals nor nursing homes. These facilities include hospices, convents, and other types of long term care settings. The rest do not fit into any of these categories, or are simply marked "other". Despite the fact that the proportion of those dying in "other" locations increased slightly between 1989 and 1998, the

**Table 6: Place of death from cancer by race and ethnicity, New Jersey, 1998**

Place of Death	Non-Hispanic			Hispanic
	White	Black	Asian	
<b>Inpatient</b>	<b>39.33</b>	<b>58.51</b>	<b>60.25</b>	<b>53.33</b>
<b>Outpatient or ED</b>	<b>1.30</b>	<b>1.63</b>	<b>1.34</b>	<b>2.38</b>
<b>Dead on arrival</b>	<b>0.24</b>	<b>0.40</b>	<b>0.29</b>	<b>0.00</b>
<b>Nursing home</b>	<b>13.17</b>	<b>1.73</b>	<b>9.58</b>	<b>4.29</b>
<b>Residence</b>	<b>43.80</b>	<b>28.99</b>	<b>22.22</b>	<b>38.57</b>
<b>Other</b>	<b>2.15</b>	<b>0.69</b>	<b>5.08</b>	<b>1.43</b>

reason is not clear, as the distribution of "other" deaths by location does not reveal any particular pattern. The trend toward more out-of-hospital deaths might lead one to expect an increase in deaths occurring in non-traditional care facilities such as hospices, but these data provide little evidence of that pattern.

#### **IV. Conclusions**

The sharp decline in the proportion of deaths occurring to hospital inpatients most likely reflects a growing preference among patients for death in a natural environment surrounded by family and friends. This trend is consistent with the current debate over assisted suicide and the increased popularity of end-of-life directives, many of which are geared toward preventing artificial resuscitation. The racial and ethnic differences in place of death that are observed in New Jersey are therefore potentially indicative of disparities in quality of care. While these differences may reflect different cultural preferences about or accept death, it might also be the case that members of racial and ethnic minority groups and/or the medical providers that care for them are relatively uninformed about end-of-life care options. Since blacks and Hispanics in New Jersey tend to have lower income than do whites, economic pressures may make it difficult for relatives to care for the terminally ill at home. Further, racial or ethnic differences in the quality of preventive and sick care may also contribute to differences in place of death, as the health of low income blacks and Hispanics with terminal illnesses may deteriorate more rapidly, making hospital deaths more likely. A longitudinal study of a multi-racial and multi-ethnic panel of terminally ill patients would help to identify the separate influences of patient and provider preferences, medical factors, family and financial resources and other conditions affecting place of death.

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